



ADVANCE CARE PLANNING
FOR INDIVIDUALS AND
FAMILIES

HANDBOOK

MODULE 4



TOUCH
STONE
L I F E C A R E

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**MODULE
FOUR
MEDICAL
CONSIDERATIONS**



INTRODUCTION

The goal of Advance Care Planning is to aid the provision of best quality medical care that is consistent with a person's values, goals and preferences, when the person cannot voice their own decisions. This may occur as an acute event or as part of serious chronic illness.

In this Module, we'll take you through the medical considerations upon which your ACP might be based. We'll explain the process of how and when a plan is activated, what 'life sustaining' treatments actually are, and how and when to discuss your wishes and plan with those who will be making decisions about you.

The aim is to help you understand why having an ACP is so important and how it helps both the medical team treating you and your loved ones who, without an ACP, could be left to make life and death decisions without knowing what you would want.

WHEN IS AN ADVANCE CARE PLAN USED?

An Advance Care Plan only comes into effect if you lose decision making capacity. In other words, if you become unable to make or communicate your own decisions regarding medical treatment, and only in circumstances covered by the Advance Care Plan.

For example, if you had been in some kind of accident, or suffered a medical incident, were rendered unconscious and, upon review were considered unlikely to improve or indeed recover, then the doctors treating you may consider it appropriate to engage your Advance Care Plan.

Your Advance Care Plan may also be used if you temporarily lose decision-making capacity. However, once you regain capacity, your Advance Care Plan will no longer be relevant, and consent must be sought directly from you.



DO I HAVE DECISION MAKING CAPACITY? WHEN MIGHT I LOSE IT?

If you are 18 years and over, you are presumed to have decision-making capacity. No one will question this unless there is a reason to.

Even so, at some stage your decision-making capacity may become impaired by disease or injury, or even drugs or alcohol. You might lose decision-making capacity permanently (for example, if you sustain serious irreversible brain damage), or temporarily (for example, if you are put into an induced coma).

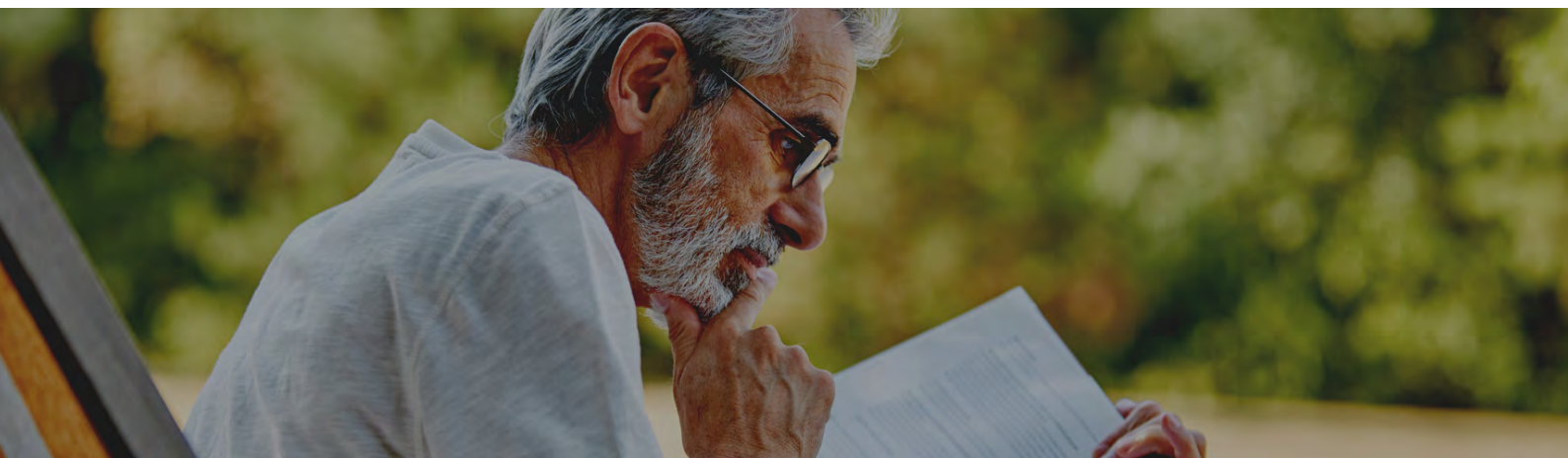
In order to have decision-making capacity for health care decisions, you should be able to:

- Understand the nature of the decision that is being made (including the information provided to you in relation to that decision);
- Understand the risks and consequences of the decision (and be able to weigh them up); and
- Be able to communicate the decision (whether verbally or otherwise)

There are different ways of assessing this “capacity” to make health care decisions. Even though you may not be able to make decisions about large financial or other matters, you might still be able to make decisions about the health care you want, especially if you have some assistance to do so.

In general, if there is any doubt as to your current or imminent future decision-making capacity, it is recommended that you be assessed by your doctor or psychologist, or other professional trained in capacity assessment. A copy of this assessment should be kept with your Advance Care Plan either digitally or on file. This will offer reassurance to anyone relying on your Advance Care Plan at a later date, that you understood your decisions when making them. It will decrease the likelihood that your Advance Care Plan will be disputed or challenged.

Remember, even if you have dementia or are unable to understand some things, it does not necessarily mean you can't make an Advance Care Plan. Ask your doctor or get a referral to someone who is skilled about supported decision-making. A doctor, psychologist or specialist trained in this area can assess your capacity to make health care decisions (or the capacity of your loved one) and skilfully help you make, document and share your decisions about your Advance Care plan.



WHAT HAPPENS IN AN EMERGENCY?



If you lose decision-making capacity, medical treatment may be given without your consent in an emergency for up to four hours if you are at risk of losing your life or a limb if:

- it is not known whether you consent; or
- you are not known to have previously refused consent.

However, if you have a valid Advance Care Plan in which you refuse consent to treatments such as a blood transfusion or CPR, you cannot lawfully be given these treatments.


If a copy of your Advance Care Plan is not immediately available in an emergency, a health practitioner may need to administer life-saving measures until they can contact your next of kin or someone in your family familiar with your Advance Care Plan.

Or they may delay treatment until they find your family and can have discussions. This may mean you suffer longer or do not get the best quality care in the shortest possible time. It is therefore crucial to ensure your loved ones are aware of your Advance Care Plan and understand its contents.

HOW DOES A HOSPITAL KNOW ABOUT SOMEONE'S ADVANCE CARE PLAN?

If possible, the hospital will be advised by you or your family that you have an ACP when you are admitted. The hospital can also contact your General Practitioner if you or your family are unable to tell them - this however is made more difficult when the emergency occurs out of hours.

You should upload your Advance Care Plan to My Health Record. This can be done by scanning a paper copy, saving your plan as a PDF and then uploading.



If the hospital or treating doctor accesses My Health Record and finds an ACP, they will try to confirm it is valid, relevant, accurate and up to date. They will need to consider the ACP and consult your Substitute Decision Maker to make decisions about treatment and care.

It is worth remembering that My Health Record is controlled by you, the patient, so if you change, edit, amend or retract your existing Advance Care Plan it is your responsibility to also update your My Health Record immediately.

We recommend you also keep an up-to-date hard copy of your Plan in your home, handbag or wallet in case of an emergency, or a copy of the link to it if digitally available -like [Touchstone Life Care's](#) digital plans- in case you are taken to hospital from the site of an accident, or you are alone at the time of admission.

It's easy to forget to update your plan and before you know it, 3 or 4 years have gone by. So try to set a time each year when you go through your plan, update it and discuss it with those who you are relying on to make decisions for you.



THE VALUE OF GOING DIGITAL

The reality is we live in a digital world and when it comes to implementing an ACP, time is everything. Digital ACPs can usually be accessed faster so you get better care more quickly.

Pieces of paper get lost, are illegible, or end up in the wrong person's file. They increase the possibility of legal challenges because of the conflict and confusion they often cause. And it can be hard for people to remember who they gave copies to. Often the thought of having to re-download, re-write, redistribute and ask people to ensure they destroy old copies of a plan may be too much to ask - especially if you are already unwell. But even if you are 100% fit and healthy, the process above can easily go awry.

Unfortunately, health care systems are also fragmented - companies change hands, staff leave, new processes get introduced and handovers are incomplete. This means relying on verbal or word of mouth plans is dangerous and work practices such as finding and validating a plan can take a long time.

When doctors have quick and easy access to your latest plan they can treat you faster and respect your decisions. It means your loved ones are spared undue stress and anxiety because they know what you would want them to do. And for you, the ability to securely create, update and share your Advance Care Plan means you can spend less time worrying about the end of your life, and more time living well, now.

HOW COMORBIDITIES INCREASE THE NEED FOR AN ADVANCE CARE PLAN

It is important to remember that creating your Advance Care Plan is about future-proofing your care. You may not have any issues right now, but the likelihood of developing co-morbidities increases as we age - which increases the likelihood of something major happening without warning.

Comorbidities are 'other conditions'. They may be unrelated to the major problem you have at the moment, and may not be the cause of it, but they may make it worse, or make your recovery from it more difficult. Therefore they affect medical decisions that are made about you.

Comorbidities can be mental, emotional or physical conditions. For example when someone has dementia, they are at greater risk of experiencing falls, malnutrition, pneumonia, or dehydration. In this case, the problem that takes the person to hospital might be dehydration, but their comorbidity, that will also affect them, is dementia.

You may be at risk of, or diagnosed with a serious condition that will affect your recovery from an accident or other problem such as dementia, chronic kidney disease, diabetes, Chronic obstructive pulmonary disease (COPD), or heart failure. In this case you need to discuss with your doctor the impact these will have on you in a severe illness and outline care choices that might need to be made in the future.

Without an Advance Care Plan, the care of someone with comorbidities - for example dementia (an illness that in itself may affect an individual's capacity to make decisions for themselves) - can leave doctors and families with difficult discussions and decisions to make.



LIFE SUSTAINING TREATMENTS

The core of an Advance Care Plan is communicating specific preferences about life sustaining treatments. Whilst the name may seem self-explanatory, the reality of what these treatments are, is not.

Basically, a life sustaining treatment is anything that is needed to prolong a person's life. They do not necessarily save or improve the chances of a person's survival.

These may include the use of:

- Cardio-pulmonary resuscitation (CPR)
- Blood transfusions
- Intravenous or nasogastric feeding tubes to provide hydration and/or nutrition
- Life support via intubation

It is worth noting that while your ACP can inform doctors as to what treatments you do and do not wish to receive - your treating doctors do not have to offer any treatment they feel will not benefit you. This is something that relatives may find hard to understand or accept. Just because you say you would like a certain treatment in your Advance Care Plan does not mean the doctors HAVE to give it to you, if it is not a medically appropriate treatment.





WITHHOLDING OR WITHDRAWING TREATMENT

One of the hardest aspects of end-of-life treatment - often more so for those left behind - is the withholding or withdrawing of life-sustaining treatment. However, you should know that it is a normal part of the process of caring for people at this last stage of life.

At the end of the day it is your body, and you are legally able to refuse treatment that might otherwise save your life - both verbally or in a written Advance Care Plan made when you had capacity. If you have not clearly stated that you would refuse certain treatments, then it is possible your Substitute Decision Maker could agree to your being given those treatments. Likewise, if you have not left guidelines about accepting certain life saving treatments, they could withhold or withdraw treatment that you would want to receive.

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In short- discuss as much as you can! With your doctors, your Substitute Decision Makers and all the people you share your plan with.

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And as stated previously, whilst doctors are not legally required to provide any treatment they consider to be ineffectual, they may in fact be liable under criminal or civil law if they do not comply with a legally made request to withhold or withdraw treatment.

Because of the emotional nature of withholding or withdrawing treatment, it is vital that you fully consider, discuss and outline your beliefs and choices in your Advance Care Plan. This will help avoid challenges and disputes arising from differing opinions around what you “would have wanted” if your family is left to make a decision on your behalf.

UNDERSTANDING PALLIATIVE CARE

Palliative Care has been in Australia for years but is often misunderstood. People often think that palliative care just means they stop treating your illness and only treat your pain. Actually, it has a lot more to offer than just pain relief.

Palliative care is for when you decide that focusing on improving your quality of life is more important than focusing on curing your illness or disease.

The word 'palliative' means to lessen. Which is why the aim of palliative care is to lessen (or palliate) suffering and symptoms.

Palliative care can help at many stages such as:

- **as soon as someone gets a diagnosis**
- **early in a disease**
- **in the middle of treatment**
- **at the end of life (called terminal care)**

It is not something you only get in the hospital or “at the end” when all else has failed. It’s not restricted to the end of life and it’s about more than pain relief—although that is an important first step.

Palliative care can involve relief of pain, but also relief of other symptoms such as bowel irregularity, loss of appetite, nausea, restlessness, itch, or sleeplessness. It can help while receiving chemotherapy, radiotherapy or other treatments. Palliative care can even mean arranging family visits, discussing spirituality or organising finances. Importantly, anyone who wants to listen, can provide palliative care. It doesn’t only come from a specialist.

Some people visit a palliative care team as soon as they receive a diagnosis, others after they have an operation, and others when they decide to stop chemotherapy or want to stop another treatment. It’s up to the person. You can access palliative care in your own home, in a hospice, or any outpatient community setting.

Palliative specialists are trained to listen and not judge. They have skills in talk therapy as well as medicine and nursing. They are compassionate and put your needs first. They can help with:

- Physical suffering such as vomiting, restlessness, itch, pain, lack of appetite, sleeplessness.
- Mental or emotional suffering such as fatigue, worry, anxiety or depression.
- Spiritual suffering such as “Why me?” “How can I help my children?” or even “I haven’t spoken to my sister in decades - could you see if she wants to speak with me?”

They can help by contacting family members, organising a family meeting, making sure your wishes or beliefs are respected, or discussing anything that is important to you.

Above all, palliative care teams are trained to listen and give options for you to consider – if not for now, then for later on as your illness progresses.